

Turning the pyramid upside down: examples of public involvement in social care research

October 2010

INVOLVE

Supporting public involvement
in NHS, public health and
social care research

About this report

This report was commissioned by INVOLVE

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Information about INVOLVE

INVOLVE is a national advisory group which supports the development of greater involvement in NHS, public health and social care research. We are funded by the National Institute for Health Research (NIHR).

For further information on INVOLVE please visit our website www.invo.org.uk

Information about TwoCan Associates

TwoCan Associates carry out research and evaluations and provide training and support to help voluntary and statutory organisations involve people who use services in their work. Almost all of our work is undertaken in partnership with service users or carers. For further information please see: www.twocanassociates.co.uk

This report should be referenced as:
Blackburn H., Hanley B. and Staley K. (2010)

Turning the pyramid upside down: examples of public involvement in social care research, INVOLVE, Eastleigh.

ISBN: 978-0-9557053-5-9

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Contents

Foreword	04
Thanks	05
Introduction	06
Example 1: An assessment of the accommodation and health and social care needs of Gypsies and Travellers.	08
Example 2: A survey of carers of people with heart disease.	14
Example 3: A study of postural care for children with disability in mainstream schools.	18
Example 4: An evaluation of a teenage pregnancy prevention strategy.	24
Example 5: A study of adoption support services.	29
Advice from the interviewees	36
Concluding comments	37
Further reading	38

Foreword

The mythical visitor from Mars is credited with finding many things surprising, although we suspect that public involvement in research has not previously been included on the list. Nevertheless, it is quite amazing that some researchers need to be reminded to involve the public (particularly people who use services and their carers) in research that addresses some of their very fundamental and personal needs. Yet that is still very much the case.

This very helpful publication offers not only examples of public involvement in research – in this case focusing on social care and health services research broadly defined – but ends with some advice from the people interviewed in the preparation of the report, a listing of the factors that help to ensure success in involvement, and a reminder of the benefits of involvement. We recommend that social care researchers' read this well written report and we direct busy researchers attention to page 36 where they will find a clear and relevant summary of what matters to people involved in research.

At the NIHR-funded School for Social Care Research (SSCR) we have a User, Carer, Practitioner Reference Group. The aim of the Group is to advise the School on all its research related activities that contribute to developing the evidence base for adult social care practice. These activities include identifying research questions, reviewing research proposals and research reports, and championing the active participation of people who use services, carers and practitioners in all aspects of the School's work. We also make it a requirement that any piece of research commissioned by SSCR must have meaningful user, carer and practitioner involvement.

We urge researchers applying to SSCR for funding, as well as those already commissioned to undertake work, to read this enormously useful publication from INVOLVE.

Martin Knapp and Gill Hastings
NIHR School for Social Care Research
London School of Economics
and Political Science



I often say to researchers 'turn the pyramid upside down'. Often with research when you look at how the project has been mapped out – the last point is the person. And I have said turn it upside down. Start with the person – then it should evolve from there.

(May Griffiths, Example 2 p17)



Thanks

We would like to thank all the people who kindly agreed to share their experiences of user involvement:

Imogen Cooper
Jennie Fleming
Sharon Godden
Margaret Greenfields
May Griffiths
Eve Hutton
Judi Mortimore
Beth Neil
Lesley Swithenbank
Greg Yates

We are also very grateful to members of the Strategic Alliances Group for all their expertise and guidance:

Richard Baker
Sue Banton
Angela Barnard
Simon Denegri
Stuart Eglin
Poonam Jain
Maria Palmer
Mark Petticrew
Laura Serrant Green
Christine Vial

We would also like to thank Maryrose Tarpey and Helen Hayes from the INVOLVE Co-ordinating Centre for their advice and support throughout this project.

Introduction

This report provides real-life examples of how service users and carers have been involved in social care research. The aim is to highlight the benefits and illustrate the lessons learnt – so as to encourage other social care researchers to consider involving service users and carers in their work.

The examples in this report were chosen to include different approaches to involvement, different kinds of research projects and the involvement of a wide range of service users and carers. The aim was to capture the lessons learnt from people's experiences, not to evaluate either the involvement or the research.

We interviewed one researcher and at least one service user or carer from each project, using a standard set of questions. These questions were based on a review of the literature around the impact of user involvement (Staley K. (2009) Exploring Impact: Public involvement in NHS, public health and social care research. INVOLVE, Eastleigh). The service user member of our team carried out the majority of interviews with the service users and carers. All the interviews were taped and transcribed. We then wrote up the examples and sent these to the interviewees for checking prior to publication.

If you'd like to find out more about the involvement of any of the projects included in this report, contact details for the researcher can be found at the end of each story. Further details including published reports and links to the project websites can be found on the INVOLVE database (www.invo.org.uk/Projects.asp).

How to use this report

This report aims to be a useful reference for social care researchers. Through these accounts, the researchers, service users and carers offer tips and advice based on their experience of involvement. These cover a wide range of issues you might want to think about for your own research. They may help you to prioritise a particular area of involvement – it's not necessary to do everything at once. It is also important to remember there is no single 'right way' to involve service users and carers. You need to be prepared to take risks and make mistakes. You might find it easier to start with a simple model of involvement – do it well – and then set your sights higher.



Look for opportunities to maximise involvement. Ask yourself how can we profitably and meaningfully involve people in a way that will be of mutual interest. It doesn't have to be all the way through. For example, it might not always be appropriate for service users to do interviews – so then involve them in an advisory capacity. But you shouldn't do it for the sake of it. Each time it's got to be on its own merits. It's got to be designed for purpose – to suit your particular piece of research and the people you're aiming to work with.

Advice from a social care researcher



Terms used

The term '**social care**' covers a wide range of services which are provided by local authorities and the independent sector. We have used this broad definition of social care in describing social care research.

We use the term '**service user**' to include:

- people who use or have the potential to use health or social services

We use the term '**carer**' to include:

- informal carers
- parents/guardians

We use the term '**involvement**' as defined by INVOLVE (www.invo.org.uk):

An active partnership between the public and researchers in the research process, rather than the use of people as the 'subjects' of research. Active involvement may take the form of consultation, collaboration or user control. Many people define public involvement in research as doing research 'with' or 'by' the public, rather than 'to', 'about' or 'for' the public. This would include, for example, public involvement in advising on a research project, assisting in the design of a project, or in carrying out the research.

Example 1:

An assessment of the accommodation and health and social care needs of Gypsies and Travellers.

Who we spoke to

We spoke to Margaret Greenfields, Senior Lecturer in Social Policy, from Buckinghamshire New University and Greg Yates, a Gypsy Advocate for the Clearwater Gypsies in Chichester.

Background

Margaret and Greg worked together on an assessment of the accommodation and health and social care needs of Gypsies and Travellers in Cambridgeshire. Members of the Gypsy and Traveller communities were involved in the steering group overseeing all parts of the project. They also developed and helped to run focus groups with younger and older people. Local Gypsies and Travellers were recruited as peer interviewers. After training, the peer interviewers carried out face-to-face interviews with their local community. They were also involved in the analysis and write-up of the results and the launch of the final report. This model of involvement has been recognised internationally as a model of best practice. It has since been used to carry out similar assessments of Gypsy/ Traveller needs in other parts of the UK and Europe.

Margaret's experience

Why did you want to involve Gypsies and Travellers in this project?

When you're working with a community that has experienced a huge amount of discrimination and oppression – you can't just walk in and expect they'll tell you everything you want to know. We had to earn their trust – by demonstrating that we were working in partnership and that all parts of that partnership were working well.

And it worked. The local community were able to trust us because we were vouched for by the people involved. Having those people on the spot meant that they could put the word out – that this survey was taking place and that we were people who could be trusted.

And how did you find people to get involved?

We wanted to have equal engagement of English Gypsies and Irish Travellers because we knew we needed to interview both those groups and there wasn't a huge amount of communication between the two. So we spoke to a nationally-based group that had credibility and respect in this area. They had already been successful in bringing those two groups together. We asked some of their members if they'd be willing to join the project steering group – because it was very important to have that buy-in from people who could speak to the different communities. By bringing in national figures, we then got buy-in from the local community. It avoided suspicion amongst the local Gypsies and Travellers who didn't know us or our work.

We recruited local people to be peer-interviewers largely through word-of-mouth. The people we had recruited nationally were able to tell us if they knew people in the area who had good potential for this type of role and were 'sound' (trustworthy and discreet). Via the local council, we also contacted the local Traveller Education Service. They were able to identify several Gypsy/Traveller women who were working as educational assistants. We invited these women to a meeting about the project and got some excellent interviewers that way.

What made the involvement work well?

Trust. I can't say that often enough – trust, trust, trust and trust.

We were very open. Because of the history of Gypsies/Travellers being exploited, there were concerns that we would come in, write up a report, get paid vast amounts of money, go away and there would be no change. So we were open – we talked to the people involved throughout the project saying we cannot guarantee what will be delivered at the end of this, but we will do the absolute best we can. We work in partnership. We are with you every step of the way.

We were also open about the budget. We said this is how it divides up – this is what's spent on administration or petrol costs – so people could see precisely what was going on.

We paid people to attend steering group meetings. And we paid the interviewers. We were clear they were paid exactly the same as a postgraduate student – given the same training, same rate of pay, and that the same degree of professionalism was expected.

How did you support the Gypsies and Travellers who were involved?

With the people on the steering group, we agreed to have some closed sessions in the group meetings, just for the Gypsy and Traveller members. So they were able to do some work without us, to review our questionnaire and to discuss whether or not they trusted us and what we were doing.

For the interviewers, it proved crucial that we provided lots of training and support. Most importantly we provided the training that the peer interviewers said they wanted. We knew we had to include training on issues such as confidentiality and child protection for ethical reasons – but there were other things they asked for that I wouldn't have thought of, such as dealing with awkward people and how to probe for more information.

We also had to do masses of work to build up trust and to show that the interview data would be anonymised and all be kept confidentially and that our interviewers would be highly professional. Some of the local community members were concerned that the peer interviewers might gossip about them. So we had to make sure people felt they could trust the interviewers, otherwise they wouldn't have taken part.

We also had to address the concerns about the quality of the interviews that came from other stakeholders initially. Some were suspicious that peer interviewers would not be objective or would deliver poor quality data. So we built in ongoing monitoring of the peer interviewers. Academic members of the team went out with each peer interviewer at different points to watch their technique and give feedback. In fact the completed questionnaires were generally of as high quality as those administered by PhD students or 'professional' interviewers.

We found that the peer interviewers needed vast amounts of support especially at the beginning of the project – this did decrease over time. I gave them my mobile phone number so they could get hold of me anytime there was a problem. I had their mobile numbers and home numbers, so it was only fair that it worked the other way round. It created respect and trust. Not a single person abused it. People only phoned in when they were concerned. And they knew we would come out to help them.

What difference did it make to involve Gypsies and Travellers on the steering group?

The steering group helped us to devise publicity material for the study. They helped us sell the project. They made sure we explained that we would be asking quite personal questions at times – and the reasons for it and importantly that all the data would be held confidentially. They helped us get that right and that was very, very important.

They also made significant changes to the questionnaire. They included new questions on areas that we hadn't thought of – like health and safety factors on Gypsy/Traveller sites, which gave us some really dramatic results – for example we found out about the lack of fire hoses and other safety issues on some publically owned sites – which we wouldn't have heard about otherwise.

With other questions the steering group members were able to say – don't be silly if you ask that, you won't get any answers and people will walk away. If those questions had to be included to fulfil our contract, then we had to say we can't completely remove that question, so how do you suggest we rephrase it to get it answered?

What difference did it make to involve Gypsies and Travellers as researchers?

It meant we could get out and talk to people who had never been interviewed before. So we learnt much more about the depths of exclusion experienced by some community members. For example, we found out about some disabled people who were living in trailers that weren't adapted in any way and who simply didn't know about relevant services or their rights to access services.

How did involving Gypsies and Travellers make a difference to the outputs of the project?

At the final launch we jointly presented the findings from the project and the Gypsy/Traveller members received their certificates of training as a community interviewer or steering group member – like a graduation ceremony. This meant that the people we involved felt incredibly valued and it went down amazingly well. It also meant that the staff from health authorities and social services as well as local councillors, who had never met Gypsies/Travellers before, had a chance to set aside their prejudices, communicate and listen for the first time. That was incredibly valuable.

Did it make a difference to how the results were used?

I think in the end everyone was happy with the results – the council felt that they got an accurate picture of what was going on in the community and the community members felt that they had been involved, so they were happy with the outcome. So then at the start of any subsequent political or legal process, we were going to be in a win-win situation. It's not that the council put down some figures and the community said this is completely wrong – you haven't consulted us. There's more cohesion from the beginning, because everyone has been in dialogue. We're not immediately at loggerheads.

What has been the long-term impact of the involvement in the project?

As had been planned from the beginning, the project helped to establish local Gypsy/Traveller forums. These have continued to provide a means of communication between the council and the local community long after the research project finished.

What would you advise other social care researchers about involvement?

Use this type of approach. It is morally and ethically sound. It does deliver results. It is the right way to work as far as I'm concerned and I'm unshakeable on that.

It's not the cheapest way – it would be easier to bring in experienced researchers who don't know the community. But it's better to work with local knowledge – with someone who speaks to the community, who knows the people.

And it's very time consuming. You need to have a huge commitment in terms of training and working with community members, very regular meetings and lots of phone calls with people.



The more I worked with the people on this project, the more I realised how little I knew. I would have got it wrong otherwise and might have had the door slammed in my face for asking the wrong questions!



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Greg's experience

How were you involved in the project?

When Margaret started the project she rang me up and asked me would I be involved. I already knew her because she'd done some work for us on our planning appeal. And I said I wouldn't be interested in the interviews side, but I did go up and assisted her in adjusting the questionnaire. I didn't want to go to Cambridge and interview Gypsies and Travellers that I didn't know. It was too far a distance. I've got other things to do, but I did attend two or three of these preliminary meetings.

What made the involvement work well for you?

Margaret has a deep understanding of Gypsies. She wasn't coming in from the outside. She was the most in touch with it that we've come across. She already had that understanding because of the work she'd done for years.

It was the right attitude from the start, because she was going to do an accommodation needs assessment and it was the first time it had ever been done and surely the thing to do was to ask Gypsies and Travellers to assist her.

How did your involvement make a difference?

The Cambridge project was the first one, it was a test one. So you had to get the questions right. The part I played in that – with other people – was altering the questions that had already been laid out, making them Traveller friendly. And eliminating questions that we thought would be offensive or inappropriate. Things that you couldn't ask – that you wouldn't know if you were outside the community. For instance, you couldn't have a male interviewer going and asking a Travelling woman if she was going to have a child. That was one of them that stood out. The man that wrote the questionnaire, he didn't see any harm in that at all – which there's not – but it's not something you could do, you couldn't have a stranger asking those types of questions.

I also helped Margaret find the Gypsies for the project, because they would be difficult to find for somebody who didn't know where to look. If you went with me today and said find me a Gypsy, or find me 10 Gypsies, we need to speak to them about something, we could do that. It's a simple operation. Margaret already knew about that – she understood it.

The Gypsy/Traveller assessments that were done by people that had no involvement of Gypsies have recorded ridiculous figures that have no comparison with what's actually happening. In Worthing they didn't involve any Gypsy/Travellers and recorded nil. When we did a mini survey, we recorded over 26 Gypsies/Travellers living in central Worthing in two hours. I think there are more than 100. And those results affect what accommodation will be provided for Gypsies and Travellers in the future. If you record nil, that won't work, will it?

How did your involvement affect the outputs of the project?

I think us being involved in the final thing, in giving the feedback, made it more credible. But it made the council a bit hot under the collar because we were asked to speak, because one of the things that came to light in the assessment was a council-run Gypsy site and it had no water, no electric and no sewage, but they were charging them £100 a week rent. And I said to them – once you discovered this and you were horrified I'm sure, did you respond immediately? ...Well that's not actually our department...

Did it make a difference to how the results were used?

Maybe it made life more difficult for the councils. The trouble was the numbers of Gypsies were too high. These figures starting to come in started to frighten these councils, because they thought the numbers were too high.

Not all the research firms that did these assessments did it our way, and you can understand the council not wanting to do it, because if you had a researcher not finding any Gypsies that's in their favour...

What has been the impact over the long-term?

I suppose it got us contact with other people like councillors and people like that, it got them to us as it were. But then whenever they had their little pet hobby project they would get in touch with us – so we became a thing called a gatekeeper, which was someone who could get in touch with the real Red Indians. They could contact us and we would say whether you could talk to the Indians or not.

Now there's always somebody coming here for something. There was a man from a United States university came here the other day and he's made a living out of our case. He read it from newspaper articles, and he got in touch with Margaret to find me. He teaches about us here as a subject. I think it's geography...

But it doesn't help me. How would it help me? They're not paying me are they? If they were paying me, then it would help me. Money would help me. Them talking to me doesn't help me. Giving me planning permission, that would help me. Changing the ability to get something passed – that would help me. Ringing me up and asking me questions doesn't help me.

I think it's Kennedy isn't it, ask not what your country can do for you, ask what you can do for our country. Well, ask not what we can do for you, ask what you can do for us, that would be a good start. That would be change wouldn't it, come here, go away and achieve something for us. That would be a change.

Has it made a difference to you personally or to the other Gypsies and Travellers who were involved?

Well for the interviewers, it gave them the first chance of doing that and they went on and did further work.

In the end for me I think it was just a job, and Margaret did pay, which makes a difference. We just would not be going to Cambridge and spending a whole day unless we were getting paid. It's a day's work. But for what? It didn't suddenly change. We didn't see the light. We didn't rise after three days and everything changed. This is just another piece of another project, of another job going on.

The problem is I don't think we've got any power whatsoever. I think, whatever I say or do will not affect anything in my lifetime. That's why most Gypsies don't get involved. But you see if there's no change, no money, where's the gain then? You might as well be watching Coronation Street hadn't you?

What would you advise other social care researchers about involvement?

Use the Cambridgeshire model. It was the first one and it was the one that should be followed.

If you could pay people some wages for the job it would be a lot better. Margaret I think was the first one that did give some money for this job. You see we've got the Tesco problem the same as everybody else. If you go to Tesco's and you get to the till and they say have you got the money and you say no, but I was with a researcher all this week – they don't let you out! You have to have money.

And a lot of the time government organisations etc are disappointed with the quality of the people that they get from the community. But who is going to give up work to go and help, if you don't get paid? You only get the old, the frail and the sick that have got nothing else to do. Our time is just as valuable as everyone else's and we should be paid for that experience.



I would say find yourself a Gypsy and then they will guide you where you want to go, whatever your project is, health or education, morality, mental illness, whatever, we'll roll you out who you need.

Greg



Example 2:

A survey of carers of people with heart disease.

Who we spoke to

We spoke to Lesley Swithenbank, who is now a Cardiovascular Disease Co-ordinator at NHS Blackpool but was working with the Lancashire and South Cumbria Cardiac Network at the time of this project and May Griffiths, who cared for her husband who had heart disease.

Background

Lesley and May were co-researchers on a project that aimed to find out about the experiences of carers of people with heart disease. May was involved at every stage of the project, from coming up with the research question through to disseminating the results. The project involved sending out a questionnaire to carers in Blackpool. The findings from the survey led to the establishment of a local expert carers' programme and a review of the discharge process at local hospitals to ensure that carers' views and needs would be taken into consideration.

Lesley's experience

How did your project get started?

The whole project really came from May. It was her idea. I met May when I was working with the Patient and Public Involvement (PPI) group in Blackpool where she was a member. I was supporting the promotion and development of an educational DVD for people using cardiac services and seeking feedback from the PPI group. That was when May said she would like to do some work on the experience of carers of people with heart disease. Her husband had had a heart attack and bypass surgery which had not been as successful as we would have expected. She had gone through all that stress

and her husband had then died of heart failure. She had all these thoughts about how she could help other people and how she could have been helped in better ways. So her idea was to do some kind of survey to find out how carers felt about the support that was available for them – and to see what could be done to improve it.

At that point in time, because of the National Service Framework for heart disease, all the services were being looked at and redesigned and quality improvements were being made – but the carers didn't have as much emphasis. So this project filled a major gap. So I approached my manager at the Network and she agreed to fund the project. It was the right question at the right time.

What made your collaboration work well?

Myself and May were partners. It made it quicker that it was just the two of us. We didn't have to have a lot of formal meetings. We could just phone each other, even at night – it was very informal. We had a personal relationship really, that made it a lot quicker.

May also had all the necessary skills – I didn't have to teach her anything. She was familiar with looking at research, writing reports and adding references. So all the work was much easier.

I was also very mindful about expenses. When you're working with service users or carers you can't expect them to pay for phone calls, ink jets and stationery – they may not have an income. And you can't expect them to communicate in the way you do – they might not have the internet or an answering machine. So I did a little bit extra. I'd print things out and take them to her house, after work or at weekends. I'd email or call her first to say I'd be round and then take the report round and talk about what we had to do. But I didn't expect her to download anything. Anything you can do to reduce costs is worth doing.

How did working with May make a difference to the research?

May kept it real. She kept it focused on the person not the service which made it a lot richer. We stayed focused on what carers said and what they wanted.

May also brought a lot of skills that I didn't have. I don't know anything about living with heart disease – May did know – she knew how it felt. But she also had her own experience – her life skills. She was good at communication and engaging people.

She also had good contacts. At the beginning, she used her contacts with social services and the carers' network to bring them on board as partners in the project. That was essential to getting our questionnaire out to carers and finding the right people to work with. We also had a lot of press coverage because of May. She was able to organise a press release with the patient involvement people. So we got a full page spread discussing the outcomes from the project and interviews with carers saying what a good idea it was that they'd been consulted.

Did working with May make a difference to the outputs of the project?

At the end of the project, because May was a member of the patient forum, she was able to take our report back to them. They then took it to the Overview and Scrutiny Committee, who then asked the Primary Care Trust (PCT) for an action plan – this drove the recommendations forward. If it hadn't gone to the patients' forum I am not sure if the outcome would have been as positive. So through May we were able to take our report to a forum that would drive forward the recommendations. Change is still evolving, it's the NHS and changes take time to implement, you've got to be up front with people about this.

What would you advise other social care researchers about involvement?

You have to involve people because what else are we doing it for? Is it just for a bit of kudos or do we really want to make a difference? Where are the gaps, what are the problems – you've got to ask people. It's why we're doing it. It's got to be of importance to them otherwise they won't answer – they won't be bothered.

When you're working with service users and carers, you've got to take a risk and let other people take on responsibilities in the project – not thinking that as a health professional you are the be-all and end-all of everything you do.

Beware the funding issues. Get support from higher management, because you have to spend a lot of your work time on supporting and working with people.

Be honest and don't give false hopes. We can't promise change when we do research. We can only say we will put things forward.

Choose a topic wisely that's topical or of very high importance to the people you're working with – then you're more likely to get their engagement.



As healthcare professionals we mustn't assume we know more than anyone else does! You have to recognise that other people are experts and accept that other people have skills that will make your project work.

Lesley



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May's experience

How did you get involved in the project?

I was my late husband's carer for a number of years. I used to represent carers on the PCT forum. Lesley came to the forum and wanted to do a study on how to help people living with coronary heart disease. I suggested that people living with heart disease also includes the carers and often their families. So I suggested that might be a route to take.

What made your collaboration work well?

It was three-pronged approach. It was health and social services, service users and carers – we chatted for many hours. So the subject was approached from three different angles and we hopefully had a meeting point that was important.

We developed a partnership. I appreciated their professionalism and they appreciated my experience and knowledge. I don't doubt they have learnt from me and I have learnt from them.

How did your involvement make a difference to the research?

I came to it as someone who had lived the same sort of life as the people we were approaching to take part in the research. I was able to go to them. I not decrying the professional approach, but any research needs to be approached from the point of view of the people who are actually living with the condition.

I was someone who had lived with and cared for someone with a serious heart condition. People find themselves literally plunged into this situation – because quite often you become a carer overnight and it changes your life dramatically. So I was able to approach them as someone who fully appreciated their situation.

So we developed a questionnaire calling on my own experience as a carer of someone with heart disease. We made sure our approach wasn't too daunting for carers. It seemed to work very well – certainly from the response we got. We had a tremendous response. The response amazed us. We wouldn't have got that response otherwise.

How did your involvement affect the outcomes of the project?

Lesley and I worked on the responses and wrote a report. We produced that report and presented it with our recommendations to both the PCT and to social services. I have to say it took them by surprise.

We were asked to present to a number of areas within research and development. We went to Lancaster University, to the social services training department there. We did quite a bit of presenting for probably about a year.

Did your involvement make a difference to you personally?

I am still involved with many things as a result of the involvement. There is a national NHS Research and Development (R&D) forum with a service users and carers group and I've been part of that. I'm also on the PPI forum at the PCT school of Research and Development at Manchester University. And I also sit on interview panels for social services for potential undergraduates for Lancaster University. And I still represent carers locally for PCT and social services. I am much sought after because the voice of carers is thin on the ground.

I found at first there was some reticence from the professionals. But because I do have quite a few credentials now, when I go to a professional group I make a point of presenting my credentials, so that they know exactly who I am and why I feel I have a right to speak about service user and carer issues. And I have to say I am now being approached to do this. I don't have to go looking for it.

What would you tell other social care researchers about involvement?

Service users and carers, we want to be involved from the start, so we are actually part of the bigger process – not just coming in half way through. We don't just want to be people who are asked to review leaflets or to be a conduit to service users. We want to be part of the shaping of research.

I often say to researchers 'turn the pyramid upside down'. Often with research when you look at how the project has been mapped out – the last point is the person. And I have said turn it upside down. Start with the person – then it should evolve from there.

One of the things that's often missed is the practical needs of service users and carers. If I'm asked to do something, if you said you wanted to send me something by email, I would instantly say 'I have an email. I work from home on a second-hand computer. When I turn it on, it costs me money. When I download or print anything – it costs me money.'

If you involve people, you have to factor in the costs for their involvement – even if they are willing to give their time for free – which I often am. But if you become involved in research it costs more than time. So if people are coming to you and they have to travel – take that into account. You may need to send a taxi for them. The practical details are often the things that put people off. Carers have a restriction on their time and on the funds they can access.

I have known people who would have been invaluable to researchers but because of the practical problems that have arisen they haven't got involved. For instance with carers, you have to take into account if the carer's not there, someone else needs to be there replacing that carer – which is an obvious expense.

The most important thing with carers is to give them time to ensure that the person who is taking their place is well versed in their routine, so the carer feels confident about leaving the person they care for. You can't expect someone to drop everything – they need advance warning to organise all this.



Remember you're not working towards the patient – you're working from the patient. If you want your research to help them, start by asking them what they need and then find out what's missing.

May



Example 3:

A study of postural care for children with disability in mainstream schools.

Who we spoke to

We spoke to Eve Hutton who is an occupational therapist and a researcher at Canterbury Christ Church University, Sharon Godden, a mother of three children, one of whom is severely affected by cerebral palsy and Judi Mortimore, a mother two children, one of whom is affected by cerebral palsy and attends a mainstream school.

Background

Eve worked with Sharon and Judi on a research project that aimed to help teachers and teaching assistants support children with complex disabilities in mainstream schools. Sharon was involved from the beginning of the project and helped with the design of the study. Judi joined the project after the fieldwork had been completed and both helped with the analysis and interpretation of the data. Sharon and Judi also worked with the team on the production of a booklet 'The A-Z of postural care.' This has been made available to all the schools in Kent and has been very well received. The team are continuing to work together on a second phase of the project. This is based on the findings from the first stage and will lead to the development of training to support the implementation of good practice.

Eve's experience

Why did you decide to involve parents in your research?

We realised there were some problems with how well children with disabilities were being supported in mainstream schools. That was our starting point. But first off we wanted to explore what the issues were. So we decided to talk to some parents. We convened a meeting, a small coffee morning really, and invited parents of disabled children from the local community. It was very informal. We talked about the ideas we had and the research we were thinking of doing. It was a very interesting experience. What it revealed to us was that there were a lot of emotions and concerns amongst parents that we hadn't anticipated and it raised a lot of other issues affecting these families that weren't being addressed.

How did this early involvement make a difference to your research?

This meeting made a big difference right from the beginning. With research you might set off with a particular idea in mind about what needs to be done – then talking to other people you realise that actually, there are other issues that need to be explored that are equally important. We came away from that first coffee morning realising two things, one we were addressing an important issue and two there were other related issues to do with the inclusion of children with physical disabilities more generally.

And the thing that stuck in my mind was one parent saying 'We want to keep the kettle hot' which was about them wanting something positive to come out of this. They didn't want to be involved in something that was just going to be a talking shop and didn't lead to any changes or improvements for their children.

It was actually a really useful experience which helped us to go away and reformulate our ideas. It also strengthened our commitment to having a positive outcome to the research. We felt a responsibility in a way that perhaps you might not feel if you haven't got that involvement. The parents were very much driving the project.

How did the involvement develop?

After the first meeting, we needed to identify parents who would be willing to commit to working on a steering group, who could give more time and contribute more. We wanted them to be involved in directing the whole project. Two of the parents from the meeting agreed to take on this role. Their involvement kept us focused. It was a constant coming back to: What is important? How is this going to make a difference?

It's hard to say where the project started and ends and the involvement has been continuous – parents have been involved at every stage and influenced every aspect.

What made the involvement work well?

We were a very well-behaved steering committee. That was an important factor in terms of 'keeping the kettle hot' and not getting too academic about it. We discussed things and managed things well. Having a parent there makes sure you explain things properly – which benefits the whole group.

We always had meetings locally and at the same place. We always tried to make a date so that the parents could get there and if they couldn't, we'd meet them for a coffee in the evening to catch up. We always made sure there were sandwiches and refreshments – that was important as well.

The parents weren't paid for their time. But all their costs were paid for and they came to the INVOLVE conference and all their travel and accommodation was paid for them to attend.

How did involving parents make a difference to the outputs of the project?

At the end of the project we got some money from Kent County Council to follow through on one of the key recommendations – to provide more information for teachers and teaching assistants working with children with complex disabilities. So we decided to produce a small booklet – 'The A-Z of postural care.'

So the steering group met again and the parents gave a lot of time and got very involved in designing and writing the booklet. It was very much a team effort. Professionals tend to use jargon, but the parents made a real emphasis on making sure things were understandable.

Producing the booklet was a real sense of achievement for all of us, especially for the parents. I would hope that we would have done that anyway – but the fact that we had parents who had been heavily involved and given a lot of their time really gave us that drive to get things done.

What would you advise other social care researchers about involvement?

If you involve people the work that you do becomes very meaningful and very applied – without involvement you might not always be focused on feeding back into practice.

But you have to tread carefully. You've to think about how to draw people into discussion and give them time to express their feelings as well. I suspect that the people that do get involved are people who feel very passionately about the work and therefore there will be a lot of charged emotions. Researchers need to be aware of that and respond sensitively to any emotional issues.

It's a lot more straightforward not to involve people – certainly in terms of the time involved. We had our original idea but then we had to go back to the drawing board. We were going to put together a funding bid, but we realised we had to do more work first. So it held us up a little bit – but in a very positive way. It's definitely a stronger proposal as a result. It has taken us longer to get there – but it was time well spent.



Now I wouldn't consider doing a project without involving people – it is such a powerful and useful experience.

Eve



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Sharon's experience

How did you get involved in the project?

I was invited along to a meeting about postural management in the school setting for children with physical disabilities by the East Kent NHS Trust physiotherapy department. After the initial group meeting I did not hear anything for some time. I was then contacted direct by Eve Hutton who asked if I would like to join the Steering Committee for the project.

How were you involved at different stages?

The initial meeting was open to many parents of children with postural management concerns. It was a group of very mixed experience and a very lively debate but very positive as it gave everyone the opportunity to say what they needed to say. It was my first experience of families and service providers together as a group in one room discussing a common theme. Unfortunately the floodgates opened and everyone wanted to discuss their own individual situations.

Involvement on the Steering Committee was very different. We considered what the project was about, the direction we needed to take, the type of research required and how the research and project would evolve. We brainstormed a lot taking time to consider every idea put forward. Researchers undertook the gathering of information from the target audience with outcomes shared and discussed with the Steering Committee. Based on the outcomes the research project was moulded and progressed with a clear action plan.

How did your involvement in the project make a difference?

I think parental involvement had a big influence when formulating the research questions for the teaching assistants and teachers; not only could I relate to the daily practical issues of postural management and utilising the equipment but also the emotional issues and pressures associated with taking on such a huge responsibility of a person's physical well-being.

Also, I felt parental input had a large part to play in maintaining the focus and momentum of the project.

What difference did your involvement make to the outputs from the project?

We actually all worked together in scoping out the best method of delivering and responding to the issues highlighted from the research. An A-Z booklet evolved which was informative, fun and light-hearted. We always intended it to have maximum impact and be an invaluable resource in the classroom.

What made the involvement work well?

I was made to feel welcome and that I had a fundamental relevance to the project. We worked together as a team with a common goal.

There were people round the table that headed up the services that my child uses and in normal circumstances you wouldn't have the opportunity to meet and talk with them. It was very fulfilling to sit down in a room and actually work together, debate, agree and disagree on issues with them.

Could anything have been done better?

No, it was a really good example of doing things well. We delivered a good end-product that has been received well and in a timely manner. The whole thing from start to finish was a journey and learning curve for all, but it was focused – and a good job done.

What were the challenges for you in being involved?

Initially I felt misplaced as this was a project about children with physical disabilities in a mainstream school setting. My child has profound physical and mental disabilities and attends a special needs school so I was not aware of the daily issues that parents, therapists, teachers and teaching assistants faced in this educational setting. As the project transpired I was able to give examples and share experiences of some good working practices at the more acute end of the scale that could also be effective in a mainstream setting.

I was also required to set aside my personal situation and start to think about the issues raised and discussed from a more general viewpoint. This could on occasions be particularly difficult when there were areas of debate that were sensitive to me.

As a parent of a child with complex needs you quite naturally become very holistic in your approach to their medical, care, educational and therapy needs working with therapists of different disciplines can give rise to a siloed way of thinking which I do find very frustrating; I had to accommodate and overcome this to enable a good working partnership.

What advice would you give to other social care researchers about involvement?

I would recommend involving service users as fundamentally it can change the whole perception of the topic being researched. It 'keeps it real' and sustains a momentum and determination to provide a tangible outcome.

One difficulty I foresee would be getting the right people involved and to ensure a true representation of the end users. You may also find it's the same parents always getting involved.

A sensitive issue of involvement is remuneration for time and input. Whilst it is very fulfilling to volunteer your time with no obligations and a degree of flexibility it does raise the question at what point should I be getting paid for my input.

I used to work full-time but due to my child's health needs and the flexibility required I now only work one day a week. My employers have been very supportive and have accommodated both my family's needs and my voluntary projects. However the moral issue I have is if I can give my time voluntary to these projects should I be offering more time to my employer and also contributing financially to the household.

As a volunteer you are giving up your time and in my case that was time with my baby daughter plus arranging and paying for additional childcare for her. Also on occasions it meant co-ordinating someone to collect or meet my sons who attended different schools.

I think the question of whether or not to pay the parent needs to be carefully thought about as I think it's a dilemma that a lot of parents will be faced with.



I see the parents as experts, the service providers as the professionals – if you want to deliver a meaningful research project you need both working together.

Sharon



Judi's experience

How were you involved in the project?

I came into the project when we were looking at the results of the research and thinking about how we could take this forward and how to present the results. The research had already been done.

We were there to think of constructive ways forward and about how we could make this meaningful to people. We were putting forward the views from the parents' perspective as to some of the reasons why the issues were coming up – and whether we had encountered them ourselves.

I was also involved in producing the A-Z booklet. We met 4 or 5 times and had lots of email conversations until we got the booklet into the final format.

What was it like for you to be involved?

At the beginning I felt slightly overwhelmed. It was first time I had been involved. Also when I joined there had already been some work done. Everybody else had had more time to become aware of the project – so I was playing catch-up a bit. But as I became more involved and understood more what was going on, I felt I was being more constructive with the things I was able to put forward. It was all going into the process and being considered. The fact that my opinion was being valued made me feel I was in the right place.

Now I feel that I've participated in something worthwhile. Something useful has come out of the time that I've spent on this project. And I'm potentially being involved in developing training resources. So I'm able to follow the research through – the fact that I have got a chance to do that is good.

It has been a very constructive process. It's good to feel that you are being listened to and what you say is important. Often service users feel like they are the end of the chain – things happen to you. Giving some feedback into the system helps you feel you do have some control.

What difference do you think your involvement made?

It was good that they involved parents because otherwise it could have been very much from a therapist's view. Given that the focus of the research was on the experiences of children in schools, having parents who can see it from the other side made it more valuable. You were getting a balanced viewpoint – not just what it's like through the eyes of therapists. We helped to give a real life view.

When you have healthcare and education professionals, because of the nature of their business, they get used to things being done and thought of in certain ways. But it's different from a parent's point of view. There are boundaries that professionals have to respect that don't really matter to a parent. They just see what needs to be done. It's important to involve service users so that they can give feedback about whether things are working or where there are problems.

What difference did it make to the outputs from the project?

Having parents involved in developing the booklet was valuable because when the therapists were writing about the equipment, we were able to add experiences from parents and to use the terms used in schools. We could say what needed explanation and what didn't, as well as helping with clearer explanations. You could question the terms being used, or to see if there was another way of putting things to make it more readable and more understandable to a lay person.

One of the nicest things is that there has been a positive outcome to this. There is something concrete. Now the A-Z is in all the Kent schools and you can see that differences have been made – potentially this could happen nationally. I know that people use the word empowering – it's reassuring almost – to know that people working up and down the country with children with disabilities in schools – that they'll know they are not alone – there are

things we can do to reassure people that they are doing the right thing. The fact that I have been involved in something like that feels very good. It's rewarding to hear that the work you've done is being used.

What advice would you give to other researchers about involving service users?

It is useful to involve service users from the beginning. If a researcher has an idea then it's good to speak to service users at that stage to say – Is this going to be valuable? Do you perceive this issue as an important area to be addressed? Is this research relevant?

If you've got users saying 'Yes, that would be useful' – that gives a real value to what's being done. You're not just doing research for the sake of research.

Researchers need to think about who the research is aimed at – what outcomes they are hoping for. They need to make sure that what they're doing is relevant and appropriate. The only way to do that is by involving users.

Getting a greater degree of ownership by involving people will help things progress.



The value of getting inputs from a wide variety of backgrounds cannot be underestimated. Involving service users does give a completely different angle on things.

Judi



Example 4:

An evaluation of a teenage pregnancy prevention strategy.

Who we spoke to

We spoke to Jennie Fleming a researcher at the Centre for Social Action, De Montfort University. We also spoke to some of the young people who had been involved, but they were reluctant to take part in an interview, as they were concerned they wouldn't be able to remember much of the detail. The project finished three years ago in 2007, which is a long time ago for many people, and represents an even longer time for young people, because their lives move on very quickly. Instead we have included some quotes from some of the young people based on their feedback at the time the project ended.

Background

Jennie worked on a project funded by Leicester City Council to evaluate the local teenage pregnancy prevention strategy. Young people were involved in the project as peer researchers. They designed the information collection methods, carried out interviews with other young people in local youth clubs and schools and helped with the analysis and presentation of the findings. They also contributed to the development of the interview schedules for other interviews with parents and teachers.

Jennie's experience

Why did you involve young people in your research?

It's just the way I have always done things. I have a background in youth work and I've involved young people in all the research I've done. You get a double benefit. You benefit from the knowledge, experience and advice of the young people you work with – but the fact that you involve young people also gives you credibility with the group of people you want to take part in your research. It puts you in a better place to know how to work with young people as well as a deeper understanding of the work you do.

Since we did this project, we have been able to work with the university to employ young people on bank contracts – as Associate Research Assistants (ARAs) – so we're able to work with them on a sessional basis for a year. Over the past 12 months the ARAs have been actively involved in one big project and have been involved in an advisory capacity on other projects. They are also thinking about how they might take forward their own piece of research.

In the past our formal contact with young researchers finished when their specific project came to an end. So employing ARAs is a good way of keeping people on board after a project has finished and making the most of their new skills and experience. Young people tend to move on very quickly in their lives – so being able to keep them involved in this way helps us to get the most out of our investment of time and resources. It also means we can involve them at much earlier stages of a project (e.g. writing bids). It's a more satisfying experience for them too.

How did you find the young people to get involved?

We made flyers and advertisements and sent them out through the agencies which were part of the teenage pregnancy prevention strategy board and through the youth clubs. Connexions was part of the board and they offered to employ the young people for us. They were part of the recruitment process and the young people's contracts were with them.

We got a big response. So we invited them all in for an 'information and selection' day where they could find out about the project. Young people often don't know what research is. So we talked through different news articles for them to think about evidence and how much credibility you give to different information. So they got a better idea about what we were going to do. We also got them to do tasks that helped us to make an assessment of their skills and abilities to do the job. We thought all the young people who were prepared to make the commitment were up to doing the job – so we offered a post to all that wanted it in the end. We took on more people than we had expected – because a lot of them turned out to be young parents (although that wasn't our intention) – so we knew there would be availability issues. We had a team of eight young people – 7 young women and one young man and all but 2 were parents.

How did their involvement make a difference to your project?

The young people made a big difference to the part of the project that involved interviewing other young people. They decided what methods to use, helped us decide what questions to ask and which local schools and youth clubs to work with. They were really reflective about collecting this information – along the lines of – 'If I was in school and people were coming to ask me about this – who would I rather talk to?', 'What would I think if someone asked me that?'. They did all the information collection with young people – both through one-to-one interviews and facilitating group sessions.

They also influenced other parts of the project through raising questions and making us look at things in ways we wouldn't have thought of. For example one of the things they talked about beforehand (that was confirmed by our research) was that the people they really wanted to talk to about sex and relationships were their parents. But their parents couldn't do this. They pointed out that it was the parents who needed most help. So that prompted us to ask parents more about this in our interviews than we might otherwise have done.

What difference did it make to involve young people as interviewers?

I don't think there's any way, that without their involvement, we could have got the sort of data that they got – even if we had had an advisory group and used their questions and advice. Without a doubt they had it.

There were times when we thought they were brusque in the questioning but the other young people didn't mind. As adults we use politeness to show we are respectful of young people – but the young people didn't feel the need to do that amongst themselves.

And there's also no doubt that young people were really impressed to see other young people in this kind of a role. At some of the youth clubs, the workers said how good it was to see how young people can be involved in research.

How did you train the young people who were involved?

We provided a lot of training and made sure that it met their needs. We did it over a number of short days. The young people were paid to attend the training, as it was an essential part of their work. We held it at Connexions and organised a lunch but importantly we also had to organise a crèche. Some of the young parents had never left their children in a nursery before. So we had a day before they started, where they could take the children to the nursery for a while and stay with them, as a way for them to feel comfortable leaving their children.

We covered a lot of material around methods – what is research and evaluation, different information collection methods and they considered each method's advantages and disadvantages – and in so doing built up decisions for what we were going to do in the project. So the young people decided how we would collect the information.

And we did a lot around ethics and informed consent and confidentiality. They were very anxious about two things – child protection issues, in particular what would happen if someone told them something they were concerned about. And secondly what they would do if the young people they were interviewing weren't interested or behaved badly or were rude. So we did a lot of role-playing and rehearsed exactly what to say in the interviews, so they could also develop all the wording about introducing the project and explaining the ethical and confidentiality issues in a way they were comfortable with.

How did you support the young people during the project?

The young people never went out to do interviews on their own. They were always accompanied by somebody from the University. We would arrange to meet up in town and then go to the site together in a taxi but at the schools and youth clubs they did all the interviews and facilitated the group sessions themselves.

Some of the young people also came with personal issues that we were not able to respond to and maybe it was not our responsibility, but we did know where they could go to get the appropriate help. So we didn't counsel people. We suggested people and places that could help them, and then we checked they had been and were getting support.

How did involving young people make a difference to the outputs of the project?

The young people helped us to analyse the findings and draw out the recommendations. This had an enormous impact. Because we gave the commissioners action points which had quite clearly come from the young people's analysis of the findings – nearly all of them have been implemented. One of my colleagues bumped into one of the staff on the strategy board, and they said it was the best piece of research they'd had, that they'd followed through on all the actions and that the teenage pregnancy rate is now dropping. We can't prove any connection between all these things – but there could be a link.

It also helped that one of the young people co-presented the findings and that they had all written the presentation. The fact that young people were involved gave the research added credibility as well. Not everyone would have been more impressed with a piece of research that young people had been involved in – but that particular audience was. That made a big difference to the impact of the results.

What would you advise other social care researchers about involvement?

I do think it improves research. There are different types of knowledge and understanding. It's about recognising that recognising that young people or service users not only have something to contribute in terms of answering your questions – but can actually help to frame those questions and the whole process.

You have to work with people on their terms. With young people, they don't turn up sometimes, they don't always communicate – but that's young people – that's just what happens. If you engage with young people, you just have to accept that that's the case.

It makes the research more interesting for other people. We ask quite a lot of people in terms of giving their time to OUR projects and OUR interests. The least that we can do is to make it as interesting and pleasant as it can be and I think involvement helps to do that.

You do have to believe in it and believe in the underpinning values of it to be able to do it – there's nothing worse than tokenistic involvement.

It takes an awful lot of time, but I am 100% convinced that it's worth it.



Service users bring different knowledge and experience and ways of looking at the world. It's not just that two heads are better than one – but that two different heads are even better.

Jennie



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The views of some of the young people involved in this project

These are direct quotes from the individuals involved in response to an evaluation of the involvement at the end of the project.

Why did you get involved in this project?

I got involved because I wanted to make a difference to how sex education in school is taught and to the information that is available to young people.

How did your involvement make a difference?

We had a real influence into how the research was done. We worked on the questions and what to ask and how to word them. We chose the exercises and what to do in the group sessions.

What helped you to be involved?

The training – it was a lot better than school – if school had been like this I would have got higher grades.

What difference did it make to involve young people as interviewers?

I think it helped we were young people – the people we interviewed could see we were their kind of age and so felt more relaxed to speak about sex ed. and services.

Some of the young people asked me how we got to do this – they were really interested in the fact we were young people, but doing this job.

What was difficult about being involved?

I was really nervous at first, but I got more confident as it went along.

The early mornings!

Waiting for the taxis in the rain.

I found leaving my daughter hard – I had never done that before, but actually she loved nursery, it was me that found it difficult.

When my daughter was sick and I couldn't make the meetings and so missed stuff.

How did being involved make a difference to you personally?

Being a part of the research team has been a great experience for me and a step up the ladder. When I started I wanted to gain experience in research but it made me discover a new found love and interest which was working alongside young people and helping them. It gave us as young people a chance to be heard and will hopefully make a change in the way some things are done for young people and knowing I was a part of that is an achievement within itself! I would do it again anytime and would like to thank the researchers for making me a part of that, because of them I am now doing a job that I really want to do.

Two of the young people involved submitted their portfolio and gained accreditation for an Open College Network qualification. Both felt very proud of their achievement:

“

So exciting, that has got to be my best achievement so far... It will look good on my CV and help me get a job doing youth work maybe one day... It built my confidence.

”

Example 5:

A study of adoption support services.

Who we spoke to

We spoke to Beth Neil, Senior Lecturer in Social Work from the University of East Anglia and Imogen Cooper, a birth mother who was an adviser on this project.

Background

Beth and Imogen worked together on a major study of adoption support that took place over a number of years. There were different parts to the study. Imogen was involved in the part that evaluated the support services provided to birth relatives, particularly the parents and grandparents of children in compulsory adoptions. Two groups of birth parents were involved. They helped at all stages of the research, except the data collection phase. They helped to plan the overall design, analyse the data and interpret the findings. They will also be taking part in the final launch.

Beth's experience

Why did you involve birth parents in your research?

We responded to a call for proposals from the Department of Children, Schools and Families. They said they wanted user involvement. So in our original draft we said we would involve people in planning the research and as part of our advisory group. But we were pushed by the funders to consider taking it quite a bit further. They indicated that they would be willing to support us financially to do something more ambitious. So our motivations were partly about satisfying the funders and partly about satisfying ourselves. When we were pushed to think about it, we thought it could be very interesting and useful. We were willing to give it a go.

How did you find people to get involved?

We wanted to recruit people who had similar experiences to the service users who were going to be participants in the research. We knew birth relatives of adopted children typically have a number of problems – such as mental health problems or learning difficulties. We knew we would be interviewing people like this. So we tried to recruit birth parents with similar life experiences.

We made use of the relationships we had already established with adoption agencies and support agencies as well as individuals. We asked the agencies to find people who matched our criteria – experience of having a child adopted and an interest and willingness to take on the role. I also contacted some adoptive parents who had been participants in a previous project of mine – so they also had some experience of taking part in research. We also wanted to involve some parents from ethnic minorities, so we went to a black adoptive parents group. The group leader circulated our publicity material to their members.

We decided to try to recruit quite a lot of people because we knew we would be working with people who had a lot of other challenges in their lives – and that the project was going to run for several years and we weren't sure if people would be able to make a commitment for that whole time. So we thought if we lose a few people along the way, we'll still have enough at the end.

Did you have any difficulty in recruiting birth parents to get involved?

One of the major challenges was to ensure that service users were clear about what was expected of them. At one of the first meetings, the service users started to tell us about their experiences of losing their children to adoption. Obviously this became a very emotional meeting with people telling their stories and people getting upset. It was very difficult for people to take in what we were wanting from them – and we were just learning ourselves.

It brought it home to us how difficult it is for people to understand what we were after and how complex the tasks are. We didn't want to say we weren't interested in people's experiences as this is exactly the perspective we needed. But we needed people to be able to focus on the study. We felt stuck.

So we decided to get our heads together with people who were working in practice. We found a woman who was a birth mother and a counsellor working with birth parents and also a person working in citizen advocacy with people with learning difficulties. They had a lot of relevant experience and helped us with the way forward.

Before we met with the second group, we did a lot more preparation. We rang up everyone who expressed an interest and went to visit people in person if we felt this was necessary – so that then people were happy to meet in a group. We also gave them an option to be involved individually.

On the day we knew we had to manage people's personal experiences. So we began with that – because that's where everyone was coming from and what they had in common. So we allowed people some space to say that to begin with, in a managed and controlled way then closed it down and moved it on. The two practitioners facilitated the day and helped with that.

We also had to be clearer about the role of a user consultant. I remember saying to them very clearly 'It's really important that you understand that why we've asked you to be here – it's about what we're hoping you're going to do for us – it's about you helping us, not us helping you'. That was a key moment. People seemed to find it empowering. They're so used to engaging with people in terms of trying to get help. It was a new idea that they were being asked as an expert to give their help and advice.

The birth parents were involved at many stages of the study, how did their involvement make a difference to the recruitment?

They made a big difference to all aspects of the recruitment. First we mocked up a leaflet. Everybody savaged it. They said it had way too much writing in it and it looked cheap. They advised us to have it professionally designed so that people would know we were kosher and that the study was respectable. They told us to put on the minimal information – just to get people to call up – then we could give all the chapter and verse on the phone. Too much detail would put people off.

They also helped us to understand what would motivate people to take part. They really emphasised the importance of saying – you'll be able to help other people like you. They advised us to have a website, to have a freephone number and to allow people to text us. Texts are cheaper and a lot of people only have mobiles.

We had to find some people via agencies. The birth parents told us that it's really important that the research team was seen as completely independent of the statutory agencies. When we sent out the invitation letters, they told us to make sure there was a stamp on the envelope and that it hadn't gone through the social service franking machine – or it would have just gone in the bin. They helped us to understand how hostile people feel to statutory agencies and social work.

After all this, we didn't have any problems recruiting to the study. In my experience recruiting birth family members is very difficult. We knew of other studies having real problems getting started because they weren't getting any response. But we met our target and within our time-scale. I think that's because our birth parents helped us get our approach right.

How did they influence the design of your study?

We had planned to do the majority of interviews by phone and the birth parents said you need to offer face-to-face interviews. So we had to go to our funders and say this might take longer and cost us more. Thankfully, they said fine, if your service users are telling you that, we will support you.

Our birth parents were also very against written consent forms, because birth relatives may be suspicious of signing anything, or may not be able to read it well or understand what they are signing. And when they looked at a draft form they said it sounded like a police caution! They said it's better if you just explain it to people and get a record of their consent on tape. We had to persuade two local authorities that we were still meeting their requirements for research governance, but they listened to us because we had the weight of the service users behind us.

How were they involved in the analysis of data and what difference did this make?

We didn't have a clue how to involve people at this stage. We looked at what other researchers had done and it seemed they just did the analysis and showed it to service users. This seemed a bit tokenistic and I felt we should involve people before we did the analysis, not after.

We had massive amounts of data and we thought it would be impossible to ask them to advise us on all of it. So we thought about where their input would be most helpful and focused on that. We didn't want them to become like us – we wanted to them to keep their unique perspective. We felt we needed to introduce them to the data in some way but also keep the confidentially.

We thought about doing a presentation or handout or slides, but then remembered what everyone had said about literacy. So we decided to present the material by audio on a cd. We selected 10 minute excerpts from some of the key interviews, and made sure these reflected the issues we were trying to tackle in the analysis. Then we hired actors to read them out and recorded it all with our digital recorder. We only paid the actors about £50 as it was an hour's work. They did it really well and read the words with feeling and meaning.

It worked incredibly well. The birth parents could relate to them immediately. People said this is the best meeting we'd had – because the interview material was so powerful.

The birth parents gave us their views on what they thought about the interviews. A lot of what they said agreed with what we thought, but some of it was really different and that was particularly valuable. For example, they rejected the idea of recovery or getting over your child being adopted – saying that you never get over it and that you only learn to cope with it better. So our analysis was then focused on the concept of coping and how well or badly people were coping with the loss of their child.

What they also brought to our attention was that what people tell us is only part of their experience and people can present themselves in a different way to the way they actually feel. We wouldn't have got that without the birth parents' insights. That really was a phase of the project that we understood how our service user can bring a different perspective – and how we can't see the world through their eyes.

How did the birth parents shape the outputs of the project?

When we had a sense of the main findings, we had another meeting with the birth parents. We made posters without much writing and lots of drawings to illustrate the main things we were going to be saying. We asked the birth parents to focus on the issue of support needs. We asked them to tell us their views of the ideal service that would meet these needs. That helped people to think out of the box and they were very creative.

But these were very concrete ideas. They made very practical suggestions. They emphasised the role of peer support much more than we would have done. I've just put these ideas word-for-word into one of the final reports. I can't really improve on them.

The launch conference is still being planned at this time, how will the birth parents be involved in that?

The birth parents have been involved in planning the conference. They said we needed to get the voice of service users across to make it more powerful. So we've been talking about people participating in the conference. A lot of them said they were willing to take part, but it's going to be a high profile event with 150 people. It's a lot to ask people to speak live and so we have decided we will prerecord it. We're going to take people to Norwich where the university has a TV recording studio. We'll ask them to reflect on their own experience and use edited highlights. Then I don't have to worry about people getting stage fright or not turning up. They are all invited so they will then have an opportunity to talk to people on a one-to-one basis. So that will raise their profile and the professionals won't be able to ignore them. We'll put them up and pay for their expenses and take them out to dinner – it will be a last hurrah!

Where has involvement made the biggest difference?

It's been important all the way along and we've got something out of it at every stage. Maybe it was less useful asking them to comment on the data collection – because that's where the gap between us and them was smallest. Because actually I've got a lot more experience than them in terms of interviewing people, but in other areas they clearly have the expertise and I haven't. Maybe it's most useful where there's really added value from gaining the user perspective.

What do you think made the involvement work well?

To some extent we were learning as we went along throughout the whole thing. But I think what helped was that at every stage, we thought it all through and wrote it all out before we began anything. And getting the advice from people with experience of working with birth parents made an enormous difference.

What has been absolutely vital is that we've had the support of our funders to do it. It was quite expensive – our budget was £12k. So we've been able to treat people with respect, to pay them for their time and their travel expenses. We could meet in nice venues, that had a nice canteen and everyone could have what they wanted for lunch, lots of drinks and cakes and biscuits. We looked after people. It backed up this message – you're helping us and we're going to reward you for that. That really helped people to understand the role.

And we've kept in touch with people – like sending them Christmas cards – throughout the whole research phase which took two years. That was a long gap – people came back three years later to help with the analysis of the data. Every one of the birth parents who started with us at the beginning of the project, has stayed with us right till the end. We didn't lose any one of them in all that time.

What would you advise other social care researchers about involvement?

Be ambitious. Don't play it too safe. We were learning as we went along. We felt out of our depth some of the time. But we got a lot out of it.

Don't just involve people who are used to being involved, or who are less troubled in life. We got a lot out of the birth parents who worked with us who had more problems.

Get people involved at the proposal writing stage to check out you're actually asking the right research questions. To give people a real say you have to get them in earlier. Our birth parents felt we hadn't invited them in soon enough. If they had been given a blank sheet they would have asked different questions to us. It made me realise the importance of involving users right from the beginning – right from when funders are developing the brief.

It takes time and resources – you've got to be committed to it. At times that's all we had – commitment. We didn't know how we were going to do it. But we were going to give it a damned good go!

It is very challenging work. One of the biggest challenges was helping people to move on from talking about their own experiences to thinking about the experiences of the birth relatives taking part in the study. We had to be quite directive about that at times. We had to be kind but firm.

Pay people in cash on the day. If they are on a low income they need their train fare back that day otherwise they will be out of pocket. We had to fight that corner with the university. We had to be clear we weren't making salary payments. But in the end they did agree to give us loads of petty cash.

Keep an open mind about what people can do and what they contribute. People will be very, very hard working and dedicated.



Given that our birth parents are people who are allegedly chaotic, unpredictable, unreliable, disorganised – they were all there waiting for us at these meetings – and they stayed all day and worked really hard. We were amazed at their dedication.

Beth



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Imogen's experience

How did you get involved in the project?

Someone at the post-adoption centre suggested it to me. After the twins were adopted, I had been really struggling emotionally with how I felt about it all. Social services, I rang them in the end. All they could offer me was three counselling sessions and they gave me information about the post-adoption centre. I saw someone there. She said I needed to speak up. She said maybe one way I could feel a bit more empowered would be to talk to these people at Norwich University doing a research project – because she couldn't offer me any more counselling. So I thought this sounded like a good idea. I'd got quite close to my mum at the time, and so I said to her 'Do you want to come to one of these meetings for people who are affected by forced adoption?' And she did and we went up and really enjoyed it.

How have you both been involved?

I took part in a group of about half a dozen ladies who had all got different stories. Everybody who was there was saying we need an avenue to speak up. The researchers made it clear it was not a therapy session. It was not dealing with anything – it was to get our experiences.

We had a series of tasks – it was about once a year we went up there, over the past five or six years.

My mum came to all the meetings. She's a very eloquent lady, she's fought for me a lot of the time and I know she's very good at putting things across well. How my mum perceived what happened is very, very different to how I perceive it and I thought it was important that as a grandparent she had her say or had a chance to put her point across. It was a bit uncomfortable. I could see the other girls were thinking – why have you got your mum there? But I hope I rose above that a little bit. It goes to show how it affects not only the birth mother but the whole of the birth family.

In July they're going to have a huge conference. I think Beth's written a book about it and there's going to be a big hyped up conference in London with the media and members of parliament to highlight the issue. We're invited to go and I'll definitely go.

What do you think made the involvement work well?

It was little things they did – like they'd always have our tea and cakes and coffee and we got a free meal. The smokers could go and have a cigarette when they wanted. You were treated really well.

You were always asked if you were OK and you could go out if it was all too much. They were aware of what potentially it's like for someone, and that they might be about to have a big wobble.

And you were paid. I think it was about £50 a day. That was good.

I also felt like the team were doing the project thoroughly. They were taking it seriously and it was a long time-scale. There wasn't just going to be a five minute interview and a report put together later that day. You got the feeling they really were researching it, to build up to this conference, with all the head psychiatrists, head doctors and MPs.

Was there anything that could have been done better?

It is very hard to be involved, because it's so personal. It's about your children, your life and it is quite hard to not be affected by it – but at the same time you know that a lot is wrong in the system and to create a change you have to work within the system as it is. Maybe it would have been an idea to have some kind of counsellor there as well – not that people weren't cared for – but so that if you did feel affected by it, you would be able to offload.

It was also quite a new thing for the team to do. You really got the impression that everyone was learning as they went along. Maybe they would be more confident in how they went about it again.

What difference has it made to you to be involved in the project?

You do feel thrown out – discarded – after what we've been through. We've been told we weren't good enough for our children. It's frightening sometimes how that can make you feel so low...but then suddenly I've felt I have got a say and people are listening and realising how big a problem it is. To get heard is quite a hard thing. And the team were encouraging us, so you just felt that if you said something they were going 'oh yes, yes, that's good.'

You were out of that institutionalised thing where people have to tick a certain box, it wasn't like that, 'Do you feel x or do you feel y? Well actually I don't feel either of those things.' They wanted to know what it is actually like, rather than trying to fit everyone into that bureaucratic 'tick the box' thing.

It made you feel that although this terrible thing has happened, I can still have my opinion and speak up and help others and be a move for change. And I definitely felt that I was part of something, something that was promoting change and awareness. You felt a bit wobbly before and after, but you ended up thinking, wow, I've made a bit of a difference, and I've actually managed to speak up about things that were wrong.

For me personally, it was very interesting to hear other people's stories. You think, 'oh wow, that was exactly what happened with me', and you don't feel so alone. And it was non-threatening, non-judgemental. There was no feeling that there was a big brother standing behind you saying 'don't say that.' You did feel free to speak.

What advice would you give to other social care researchers about involvement?

I would say pick the people you speak to wisely and check they're not still too vulnerable. Make sure they are really ready to talk about it. You can find out from whoever's working with them and you have to ask the question very sensitively, 'Do you feel ready to be part of this?'



I think the most important thing that researchers need to make clear is that they can't be a therapist or counsellor, or actually do anything about someone's case. They just have to get across that by getting involved, people are helping in a bigger way, as part of a general improvement for others.

Imogen



Advice from the people we've interviewed

The following advice on how to overcome some of the challenges and barriers to involvement is based on the experience of our interviewees. As far as possible this advice is given in the interviewee's own words:

- You have to be adaptable and responsive to the skills of the service users or carers you're working with. They may not have report writing skills, but other skills are just as important. Respect those skills even though they are not the same as yours.
- Service users are likely to be novice researchers but that doesn't make them bad researchers. PhD students are novice researchers, so service users are not unique or alone in having to learn – and like everyone else they can learn very quickly.
- Involvement can be emotionally draining if you work with people who need a lot of support – it can be very tiring. Be prepared to give a lot of time to this work.
- Some service users may still be angry or in a state of grief about their life experiences. Getting involved in research is a way for them to channel their emotion in a positive way. But it can be difficult to work with people who are still quite vulnerable – meetings can become very emotionally charged. It's important to manage those emotions, to have someone on board who can support them and to make sure you keep some distance.
- Sometimes – especially in multiagency projects – people can get defensive over their areas. This can be frustrating for service users – but it's inevitable that people will protect their own turf.
- You may have to fight your corner at times. Sometimes commissioners do not understand or do not politically agree with involvement in research. They may try to dominate the situation and control things. It can get ugly on occasions!
- Be prepared to handle the media. You can get adverse coverage and negative comments from people who don't understand involvement.
- You need an exit strategy. Service users and carers can give a lot of input to a project and then they're dropped at the end. It's unfair. Get them involved in the follow-up work. Get them involved in other projects.

Concluding comments

This section contains the key messages from the examples in terms of the factors that ensure successful involvement and the benefits that involvement brings.

Factors that ensure success

- Building relationships – working in partnership with service users, showing you respect and value their expertise – showing that you are listening and making changes in response to their input
- Going the extra mile – making an extra effort to ensure service users can be involved in a way that meets their needs – for example holding meetings outside of office hours, printing out documents for people
- Honesty – being clear that research takes a long time and doesn't necessarily lead to change as well as being open and transparent about how you are working
- Being sensitive and aware – some topics are going to be very sensitive and emotional. You need to manage this and support people appropriately – at the same time as being clear about boundaries
- Clarity about roles – taking time at the beginning of a project to explain what you need from the people you involve and how they can help you
- Being mindful of the practical issues and minimising the costs for service users – the 'little things' really matter and can determine whether an individual can get involved
- Investing a lot of time – especially when planning involvement and supporting people during the project.

Benefits of involvement

Involving service users and carers ensures that you:

- Stay focused on the useful outputs from your research – making it more likely that your research will make a difference to people's lives
- Get the language and approach right throughout your project – in your recruitment material, research tools and reports – this is especially valuable when you are working with seldom heard groups or the topic is particularly sensitive or emotive
- Get better quality data, a more-rounded and informed interpretation of the data and findings that have greater credibility with your funders and other key stakeholders
- Gain personally from new relationships and a greater knowledge and understanding of the people you work with.
- Reach a much wider audience with your reports and presentations – in particular reaching the people who are most likely to make use of your results.

Further reading

This publication is one in a series, other titles available are:

Faulkner, A. (2010) **Changing our Worlds: Examples of user-controlled research in action.** INVOLVE, Eastleigh.

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INVOLVE is a national advisory body that is funded by the National Institute for Health Research to support public involvement in NHS, public health and social care research and development.

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